

first in the nursing home he clung to the hope that he might escape. At last his imprisonment made him despondent and despairing. "In the last two years, I never once found him reading or listening to music or talking to someone," a friend recalled. "He just lay there, looking straight up at the ceiling or dozing" (*People Magazine*, August 7, 1989, p 58).

"I don't want to live an empty life lying helplessly in a nursing home for another 30 years," Rivlin said. He came to realize that he would have "to spend the remainder of my life in an institution. . . . What pushed me over the edge was the realization that I was anchored to one spot." "If you're in a situation where you have no freedom," he said, "then you have to make a change, and my change is death."*

Despite the emotional battering Rivlin suffered, he received no psychological counseling during the two years before his death. A court-appointed psychiatrist concluded he was competent, yet Rivlin's lawyer refused to say what, if any, qualifications the psychiatrist had in the psychology of disability, a specialized field.† Rivlin was denied appropriate psychiatric evaluation and crisis intervention counseling. The nondisabled people around him assumed that when a person with such a disability said he would rather be dead, he must be acting rationally. No one helped him search for, in his words, "other ways" than suicide. The denial of appropriate counseling surely contributed to his death. It is a central issue in this case.

The conditions that led David Rivlin to prefer death have been factors in other assisted suicide cases involving disabled persons that have captured media attention. Elizabeth Bouvia in California, Larry McAfee in Georgia, and Kenneth Bergstedt in Nevada were all denied appropriate psychological diagnosis and counseling. Bouvia and McAfee were deprived of adequate financial support for independent living. The only real aid the system offered any of them or Rivlin was assistance in ending their lives.

These cases contain three lessons for health care professionals: First, saving people's lives, rehabilitating them, and teaching them the medical and physical management of their now-disabled bodies is pointless if they are denied the right and the means to control those lives. Health care professionals must support the disability rights movement's efforts to secure adequate, nationwide, government funding for self-directed independent living.

Second, health care professionals should not assume that suicidal gestures are simply a response to a person's physical disability. Social factors—segregation, the denial of self-determination, cultural devaluation—are always present and typically primary in generating such despair. For that reason, disabled people undergoing emotional crises must receive psychological evaluation and counseling from appropriately trained therapists.

Third, until people with major disabilities are guaranteed their rights to self-determination, independent living, equal access to society, and appropriate psychological counseling, medical professionals must never support or assist the suicide of a disabled person. To do so in the present societal circumstances of devaluation, discrimination, and segregation is simply the ultimate act of oppression.

**People Magazine*, August 7, 1989, p 58; *Detroit News*, May 19, 1989, pp 1-A, 6-A; "Court OKs Death Wish," *USA Today*, July 7, 1989, p 2-A.

†*Detroit News*, May 19, 1989, p 6-A; United Press International, "Man Disabled 18 Years Seeks Doctor to Cut Off Life Support," *Indianapolis Star*, July 7, 1989, p A-11; D. B. Piastro, "He Needed Help to Live," *Long Beach Press-Telegram*, August 1, 1989, p C-2.

A Disability Rights-Independent Living Perspective on Euthanasia

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THE ISSUE OF WHETHER euthanasia should be legalized in this country has been debated extensively from a wide variety of perspectives.^{1,2} Seldom, however, is it addressed from the viewpoint of persons with severe physical disabilities who wish to maintain autonomy over the fundamental decisions that affect their lives. It is from this important "disability rights-independent living" perspective that I hope to contribute to the debate.

For purposes of clarity, it is valuable to state explicitly at the outset what I do not address in this article. First, I do not address whether there should be a right for disabled people to refuse treatment—to disconnect life-support systems such as ventilators or feeding tubes—sometimes referred to as "passive euthanasia." This right has been recognized by many courts³ and is implicitly accepted in this article. Second, I do not address "involuntary euthanasia," in which there is no request by a person to terminate his or her life. The legality and morality of this practice, which is regarded as tantamount to genocide by some segments of the disabled population,⁴ must be addressed elsewhere.

Thus, in this article I address only "voluntary active euthanasia" in the disability context—whether a legally competent person with a disability (that is, a functional limitation not necessarily associated with any illness, terminal or otherwise) who wishes to die should have the right to assistance in actively terminating his or her life. While different people with disabilities differ on this issue, I believe that the view expressed here is most consistent with the philosophy of the disability rights and independent living movements—social movements initiated in the early 1970s by disabled people to pursue their legal rights and to remove environmental barriers that limit their ability to live independently in their communities.⁵

People with disabilities have an interest in the legalization of voluntary euthanasia even greater than that of the nondisabled population. Many people with disabilities have substantial functional limitations that significantly reduce their ability to live independently. Many experience severe pain or discomfort that prevents them from engaging in productive or recreational activity. After months or years of contemplating their situations, some wish to die but are unable to commit suicide without assistance. Such assistance would constitute euthanasia, which is considered murder under our legal sys-

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tem, and which, therefore, would subject the person who assisted them to legal jeopardy.

As a person with a physical disability (C2-3 quadriplegia), and as a researcher and attorney who studies health care and disability policy, I have strong feelings about the right to euthanasia. Since I was injured at the age of 16 (approximately 18 years ago), my most important objective has been to gain the fullest possible control over my life. This goal is not very different from that of many nondisabled people, but it is somewhat more difficult to achieve for people with no voluntary use of their arms, hands, and legs. Through advanced education and professional endeavors, I have been able to obtain substantial control of my life and, consequently, substantial satisfaction and happiness.

Unfortunately, many disabled people have not had these opportunities, and some live unhappy lives in which they have (or at least believe they have) little or no control. Three of my friends decided several years after becoming disabled that they no longer wished to live and committed suicide. One attempted suicide three times over a five-year period, twice wounding himself severely and painfully before successfully killing himself. All three ultimately were able to free themselves from lives they did not want. All three had sufficient functional capacity to complete the act without any assistance. For other disabled people who do not have such capacity, suicide is impossible. For them, voluntary euthanasia is the functional equivalent of suicide.

The ability to choose whether to commit suicide—to implement the decision to continue or discontinue life—constitutes the ultimate manifestation of control over one's life. People who believe they have no control over the fundamental decision to live cannot claim to have autonomy over their lives. Possibly in recognition of this, and because it is considered ludicrous by many to punish an attempt at taking one's own life, attempted suicide is no longer illegal in this country. We respect, or at least tolerate, the decision of a person capable of suicide to take his or her life. Yet we continue to prohibit people incapable of suicide from having another person assist them.

Beyond the various religious arguments, the primary contention against the legalization of voluntary euthanasia concerns its potential for abuse—that is, actual murder or emotional coercion to choose death. Appropriate safeguards to prevent such abuse can be built into a law permitting euthanasia. In the Netherlands, for example, there is no prosecution of euthanasia if a specific protocol is followed involving confirmation of the request made to more than one physician by the person wishing to die.^{6,7}

In reality, the prohibition against voluntary euthanasia in our society is based primarily on social paternalism. People with terminal illnesses or severe disabilities are considered by society incapable of making a rational decision to die. Yet, in truth, most disabled people are at least as capable as nondisabled people of making such decisions and, in the interest of self-determination, should be allowed to do so. As a person with a disability, I resent the prospect of physicians, judges, or public officials making decisions about me that are inherently personal and that fundamentally affect my life. Many other disabled people, as well as many nondisabled people, share this sentiment.

Thus, in the interest of autonomy and self-determination, voluntary active euthanasia should be legalized in this country. First, however, we must provide disabled people with the

supports they need to live in a dignified manner. Many disabled people require substantial resources, including personal assistance services, to live in their communities.⁸ Some are discouraged by national and state policies from attempting to live productively and independently.⁹ Without adequate resources and incentives, disabled people are given little reason to live. Many who are choosing suicide are responding rationally to a system that does not provide the supports they need (G. Kolata, "Saying Life Is Not Enough, the Disabled Demand Rights and Choices," *New York Times*, January 31, 1991, p B-7). Some do not want to live because they think they are imposing enormous caretaking and financial burdens on their families and friends.

Contrary to common belief, the vast majority of people with disabilities cherish life and are content to live with their disabilities until their natural deaths. It is likely that few would choose euthanasia if they had viable alternatives to meet their needs and to live with dignity. As a society, we must provide such alternatives. For those who ultimately decide that they do not want to live, we must respect their choice.

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Responding to Requests for Ventilator Removal From Patients With Quadriplegia

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RECENT ADVANCES IN MEDICAL TECHNOLOGY and the availability of emergency medical services have allowed an increasing number of people to survive serious injuries and catastrophic illnesses that permanently impair respiratory function and that require the lifelong use of mechanical ventilation. Spinal cord injury centers have developed remarkably effective special programs for the comprehensive rehabilitation of patients with high quadriplegia who require ventilator use.^{1,2} During follow-up interviews after rehabilitation dis-

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